



Neonatal Seizure Registry

Spring 2023

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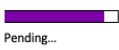
Hope for HIE

Parent Partner: Betsy Pilon

NSR-DEV Study Progress



Enrollment



Pending...



3 yr



Pending...



4 yr



Pending...



5.5 yr



Pending...



7 yr



Pending...



8 yr



Pending...

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Welcome to the newsletter for the *Neonatal Seizure Registry (NSR)*, which includes updates on all studies led by the NSR group. Thank you for being a part of this important work!



NSR-GENE recruitment has started—your family may be eligible!

Children who had seizures as newborns can develop more seizures weeks, months, or even years later. This condition is called epilepsy. Researchers know some reasons that children may develop epilepsy, but there is still a lot more to learn. This new study will use DNA from both biological parents and the child to look for genetic (inherited) risk factors for epilepsy. Samples are easy to collect – a cheek swab for kids and saliva specimen for parents – and can be done during a regularly scheduled clinic visit or in the privacy of your own home. To protect your personal health information, the samples will be coded



with a Study ID number. You may help doctors understand the risk factors for epilepsy, better diagnose and treat children with early life seizures, and develop new treatments to prevent epilepsy. *Even if your child has not experienced seizures since the newborn period, your participation is important! Local study coordinators will reach out to eligible families soon.*



NSR-DEV – Importance of the In Person Visit!

So far 85 NSR families have completed their in-person visits—thank you to everyone who participated. If you haven’t had your in-person visit yet, there’s still time! The visit takes place when your child is between 5-6 years old and lasts about 1-3 hours. During this visit to your local participating hospital, your child will have two neurodevelopmental assessments. After the study visit, you will receive a report that explains the results. **These assessments are some of the most important measures for this study, and will help researchers understand the range of abilities of school age children who had newborn seizures. To help future families, we need to follow as many children as possible during our final year of funding for this study – please sign-up!** *Our centers have COVID precautions in-place and we will do our best to make the visit convenient, easy, and comfortable for you and your child. Support is available for families who may face challenges in participating. Please contact your local team today to schedule your in-person visit and find out what financial assistance or other accommodations are available.*



NSR-RISE Research Study Update

Inflammation is the immune system’s response to injury or infection. The role of inflammation in infants who had seizures during the newborn period is not well understood. Because of this, we are studying the relationship between inflammation and seizures in infants. This study is important because it may help us to better understand whether inflammation and newborn seizures affect an infant’s risk for developing epilepsy later in life. Thanks to your help, we have finished the recruitment phase of this study and look forward to having results to share later this year. *If your family is also eligible for our new NSR-GENE study, local study coordinators will reach out soon.*



Results of your participation: Selected Abstracts for Pediatric Academic Society conference

Towards equity in research participation: Association of financial impact with in-person study participation

+ Shellhaas RA, Lemmon ME, Gosselin B, Abend NS, Anwar T, Benedetti G, Berl M, Chu CJ, Larson JC, Massey SL, McCulloch CE, Numis A, Rogers EE, Soul JS, Sturza J, Thomas C, Wusthoff CJ, Franck L, Glass HC

+ In this research, we looked at the reasons why families did or did not join the NSR-DEV research study. We also looked at which families completed the in-person visits. These factors are important because a study’s design can make it more difficult for certain groups to participate.

+ Families who joined the study were more likely to have private health insurance than families who did not join the study. They were also more likely to report child’s race as white and have mothers with more years of education.

+ Families who experienced greater financial burden and more challenges due to their child’s illness were less likely to participate in the in-person study visit.

+ The findings highlight how barriers to research participation can prevent families from joining our studies, and make it difficult for families to complete study visits-

+ Our goal is to help every child and family affected by neonatal seizures. To do that, we must work to design studies in a way that makes it possible for all families to participate in the research process. *If*

YOU are struggling to make your child’s in-person visit work for your family, please let us know! We are here to help.



Neonatal Seizures and Associated Neurobehavioral Profiles in Preschool Age Children

+ Mattes AM, Shellhaas RS, Glass HC, Sturza J, Lemmon M, Rogers EE, Numis A, Soul JS, Berl M, Wusthoff CJ, Chu CJ, Massey SL, Thomas C, Franck LS, McCulloch CE, Means J, Means K, Gidley Larson JC

+ We studied whether there are differences in behavior (e.g., attention and social behavior) among children with newborn seizures developed early childhood epilepsy compared to those who did not develop epilepsy.

+ In this group of children who survived newborn seizures, those who developed epilepsy by 24 months had higher rates of difficulty with social skills and worse functional development at preschool age compared with those who did not develop epilepsy.

+ These findings highlight the importance of early intervention services for children with newborn seizures to support healthy development in early childhood.



Did you know? Resources available on the NSR website

Families of children with newborn seizures may experience challenges related to their child’s condition – these include anxiety, depression, post-traumatic stress disorder, and more. The NSR website has resources for peer support, mental health information, and actionable steps to care for yourself and your family. No matter where you are in your journey, caring for yourself will help you care for your child. You are never alone. To explore the free resources available, please scan this QR code:



For more information about the study, please visit our website: <http://neonataleizureregistry.ucsf.edu>

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